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7-15-2003

Ray Thomas interview for the Lest We Forget Collection of Oral Histories

Ray Thomas

Jeff Moyer

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Repository Citation

Thomas, R., & Moyer, J. (2003). Ray Thomas interview for the Lest We Forget Collection of Oral Histories. . https://corescholar.libraries.wright.edu/special_ms396/8

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RAY THOMAS

Jeff: It is Tuesday, July 15, 2003. This is Lest We Forget interview series and I'm interviewing Ray Thomas. Ray, how long have you been involved in the field of work with people with cognitive disabilities.

Ray: I would say since 1968 when I worked with the day camp program for kids out at Camp Christopher. Subsequently became the executive director of the ARC of Summit County.

Jeff: Over those 30 plus years what is your experience been directly with state institutions?

Ray: Directly it has been one of visiting people who were there. Otherwise I've had no direct experience working in an institution but I have had friends who lived in them and I've gone to visit them.

Jeff: Over what period of time have you made those visits?

Ray: All through my career, as a matter of fact, I've been visiting the institutions. Not only Apple Creek but which is the most local to me but most of the institutions in Ohio.

Jeff: Can you describe what you've seen when you've been there? What was your first physical reaction to walking into a state institution?

Ray: I can remember my first visit to Apple Creek very well. It was in 1972, the first year that I became director of the ARC. I went with a group of parents from Summit County. Upon walking in just the smell of the institution nearly bowled me over. I was also bombarded with the vision of people without any clothes on. People tied to benches in the day rooms; much, much noise, very little activity going on between people who were caring for the residents and the residents themselves. I became almost physically ill on my first visit because of the conditions that I observed.

Jeff: About how many people were in the day room that you walked into?

Ray: Probably 50, probably 50 people in this particular day room. The showers were open and some people were being hosed down in the showers. This was also a sickening experience for me to see that. Clothing was in disarray on most people, where people were on the benches. Some of them were tied there in order to keep them there. Some just to keep them sitting in a sitting position. But for others it was just to keep them on the benches.

Jeff: What were they tied with?

Ray: Rags, other clothing, some with—I didn't examine the material but it looked to me like it was mostly rags, not rope or anything like that. Some were shackled as a matter of fact. There were things that appeared to me to be shackles that held people there.

Jeff: That was in 1972.

Ray: 1972.

Jeff: Through the years of your visits to other state institutions did you see those situations improve?

Ray: In later years, yes I did see conditions improve because parents of individuals who were living there and people who were in the communities began to insist that the conditions be better and that people who didn't need to be there began to leave. And that caused the depopulation and it allowed people to live in conditions that were better than they were when I first visited.

I had the same reaction when I visited Orient State Institution which has since been closed and turned into a prison, upgraded to a prison I might add. Because the conditions at Orient were just as bad if not worse than those at Apple Creek on my first visit there. Soon when Ohio needed another prison they chose Orient for that site and they closed the institution and put these people in other institutions and some back into the communities but then upgraded it and made a prison out of it.

Jeff: In your years of working as director of the ARC you no doubt were involved with advocacy and getting involved with people who needed the assistance of the ARC. What sort of abuse and punishment did you see within the institution?

Ray: Well, I saw people in isolation. I saw people who were tied as I say to the places that they were allowed to be. I didn't witness any overt misuse of the residents. I didn't witness any of them being hit or anything like that but that did go on. There's no question about abuse that did go on to the residents. But it was something that really turned me off before I visited early on I was convinced that we needed institutions in Ohio. After my first few visits I decided we didn't need anything like that at all. It became my goal, at least a personal goal of mine to see that they got closed all of them and instead we expanded them to greater numbers.

Jeff: During what period was the expansion happening?

Ray: Well, it was right after 1972, when a conference of the ARC decided that they had enough and we wanted to close the institutions, that Ohio's leaders and MRDD in Columbus decided that they were going to build new smaller institutions and close some of the older larger ones. As it turned out I think there were seven institutions when I began working with the ARC and a few years later we were up to fourteen or fifteen including the old ones which they wanted to close and then the new ones which were smaller and placed around the state. But we began to see a depopulation at the same time of people in those institutions. There were nearly 10,000 people in them when I began working with the ARC in 1972.

Jeff: Was that a high water mark in terms of population?

Ray: I believe it was.

Jeff: How many people are institutionalized today?

Ray: In the state, I think it's about 1,800 between 1,800 and 1,900 people total.

Jeff: So somewhat over 100 per each of the 14 or 15 sites.

Ray: Yes, I would say probably 100 to 200 in the sites. All of the institutions don't exist any more either. Orient closed, Cleveland Development Center closed, Broadview Center closed, there were several others of the originals that closed leaving the newer ones but still some of the oldest ones exist today.

Jeff: How old were the oldest of the institutions?

Ray: Gosh, they would go back to the early 1900s, the late 1800s, back to the time when it was felt that this was the answer, this was the way we would treat these folks. They were called hospitals at that point and I believe it would be the late 1800s, early 1900s when they were developed, the large sites were developed.

Jeff: In the years you were working as an advocate with people who were on the inside did anyone want to be there, anyone happy with the circumstances?

Ray: Not that I was aware of No, I don't believe any of the people who were confined to those institutions were happy. Some I have to say that's all they knew so they couldn't be unhappy because they began there as children and grew up in those institutions; didn't know anything else. But those who had been institutionalized when they were older were miserable. Everybody was miserable. If you went to visit an institution you were bombarded by people who wanted to touch you, who wanted to look at you, to just be with you. It was a heart wrenching kind of a thing to observe that these people were starved for affection, starved for friendship, starved for anything that would be of a normal life in my opinion.

Jeff: So the living circumstances consisted of a day room and a bedroom.

Ray: A day room and a ward in many cases, wasn't even a bedroom. It was a large ward with maybe up to 50 iron beds or cribs. There were crib wards where children were confined. They were like cages because they had covers over the top of them and then they were completely surrounded with bars. It was a crib but it looked like a prison. There were large wards that

contained these folks. They weren't small bedrooms or they weren't individual beds. They were individual beds in the wards but they were the typical institutional type bed at that time. They weren't small quarters which later the institutions got to but at that time they were large wards and they were very, very noisy and very, very dirty. Just about everything that you could think of that you wouldn't want to live in.

Jeff: The friends that you were working with there at the time, you were working through your capacity as director of the ARC under what circumstances were you brought in?

Ray: I was brought in by my board of directors who decided that they wanted to visit and observe the conditions of the institutions. That's when I went in. We tried to find people from our county, from Summit County that were confined there. We did find a number of them. At that point we were trying to plan on how we could get them back to our community because we were developing group homes and programs. The MRDD boards had daytime programs for individual and we were trying to develop community residential services and we wanted to get a count on how many of our folks from Summit County were in Apple Creek and other institutions around the state. So that's how we became interested in visiting them and seeing our folks that were there.

Jeff: What was the pattern of when one was remanded to an institution was it based on geography?

Ray: Very often, yes, but that could have been because of capacity as well. It could go to an institution in another part of the state as opposed to being the closest one which was then Apple Creek or Cleveland Development Center or one of the ones that were in Cuyahoga County. There were several in Cuyahoga County at the time. Unfortunately I can't remember the names of some of them. It's been awhile because those were all closed. The only institution in Cuyahoga County now that I'm aware of is Warrensville Developmental Center and that's a fairly new facility. It was one that was built to hold probably 200 to 250 people as opposed to 1,000 people or more that were in the old institutions.

Jeff: In the newer model, for example Warrensville, is that based on a smaller number of people living together sharing space.

Ray: That's correct. That's one of the things that the Ohio Association for Retarded Citizens at the time, which is now the ARC of Ohio, was pushing to have the institutions downsized. The new institutions that were built probably had a capacity of 200 to 250 people. There were people transferred then from the older ones to make more room in the older ones which were very, very crowded. There was a limit put on the newer ones as far as capacity. They were built in such a way that they would be able to house people not in large quarters but maybe four person bedrooms that would be closer to a community type of a residential program. But Warrensville was the most local. Youngstown was another developmental center that was built at that time and probably had a capacity of 250 people as opposed to the 1,000, at least 1,000 if not maybe 1,200 to 1,500 people at Apple Creek, maybe more than that, maybe 2,000 at one time. The smaller ones were built with the limited capacity. The older ones should have had limited capacities because they had huge dormitories and huge dayrooms. They just kept filling them up. We wanted to put a stop to that kind of a thing too.

Jeff: The advocates of Work Too see smaller facilities built. Is progress continuing toward moving people from those institutions back to the community?

Ray: I think that we're at a point in history where the institutions with having 1,800 in the state of Ohio are down to a very workable population. But our goal at that time and still is to close them all. We don't think anybody needs to be in them, that they should be able to come back to the community, that the community can handle their needs. The community has demonstrated that ability to handle their needs.

Jeff: As people came back from the institutions into the community what was the state of their medical and dental health?

Ray: Well, some people were in bad shape and other people were in good shape. I guess it depended upon how attention you got in the institution you were in. A good friend of mine, a classmate from grade school, wound up at Apple Creek, went there shortly after he was in his teen years and lived there for 25 years. His physical condition was terrible when he came back to the community. He was one of the first people that we brought back. He lived in group homes here in the community for another 25 to 30 years. Always needing medication, medication is part of what did him in. He finally died a year and a half ago in a nursing home here in the community at age 67.

Jeff: Why had he been institutionalized?

Ray: That was what you did at that time if you had a child with a disability. Most people, the only option for them was to institutionalize them. This particular gentleman's parents kept him at home until he was finished with grade school. He went to grade school with me which was an unusual situation. He didn't have to go to a special school. Maybe if there was one available that's where he would have gone but the unusual part for this gentleman's early childhood is that he did go through a normal grade school. That was the only option for him when he became a teenager. When he became a teenager he was very difficult. He was seen as being a threat to other children. Although I can't remember that he ever did hurt another child. But there were circumstances that he would wander and people were afraid of him based on that because he did get to become a very large person. Mostly it was from fear that he was probably institutionalized. His parents, now that I think about this particular gentleman, his mother became ill, died when he was still in his teenage years and his father just didn't want to be responsible at that point. So they institutionalized him.

Jeff: The types of behaviors that you describe in the day room that you observed that caused people to be restrained there's a category called institutionalized mental illness. As you've seen people move back from the institution to the community what have you observed about people's behavior?

Ray: The behavior of a person who comes back to the community generally as I have seen they become more like the people that they come to live with and associate with than the people that they associated with in the institution. Many of these behaviors were learned from other people who in the institutions with them. They lost those behaviors many of them when they came back to the community, not all of them did but most of them did. They began to be able to live a more normal life and they were able to be treated for the conditions that they had many times where they weren't treated well in the institutions for the conditions that they had.

Jeff: The treatments that the people received in the community then when they're designed around the individual need are successful in general.

Ray: In general, they are successful. Because, yes, the individual is assessed and his needs are prescribed independent of a general prescription of need. In other words whatever he needs he should get and that's what we've seen happen as people came back to the community. If they needed medical assistance they got it. If they needed psychological assistance they got it. If they were able to live more independently they got to move into a more independent setting because of that. The original group homes in the community were large and not too dissimilar from an institutional setting themselves because of the numbers of people that were there. We quickly found out that we needed to make those places smaller and more suited to the needs of the people who were living there instead of a generalized condition that people with different kinds of problems would be associated altogether. We tried to isolate people to the kinds of a setting that they needed and could be prescribed care for. That seemed to work better in a smaller, we quickly went from 15 and 20 people in group homes to 8 and even down to 5 people living in one particular facility. Now I dare say there's not a group home in Summit County that has more than 4 people living in it. So we quickly got to a position of down-sizing those group homes to facilities

that were much more suited to the individuals and conditions that were much more suitable to the individuals.

Jeff: The stereotype and fear-based rationale for not having people with cognitive disabilities living as neighbors living inclusively in the community sounds very much like what you spoke of with rationale of your friend who was institutionalized, community fear. What do you have to say about that perspective in today's world?

Ray: In today's world it's not nearly as hard as it was when we began to put group homes in our community. There were huge outcries from neighborhoods and from individuals who were going to be living close to those folks that they didn't belong in those neighborhoods. There were zoning laws at that time that precluded certain numbers of people from being in a community facility. There were neighbors who had a great fear of the individuals who were coming back from the institutions and so trying to establish the original group homes was very difficult. There were public hearings. Some people got very nasty in the neighborhoods about the fact that they were going to be subjected to a group home in their neighborhood. This quickly passed as we had people actually be able to live in those communities and neighborhoods and people observed that this isn't such a bad thing. In fact, engendered support among neighbors in a lot of communities for the group homes that were placed there. There began to be interaction between people in the neighborhoods and people who lived in the group homes. So it was a matter of acclimating the community, educating the community about the kinds of people that were coming to live with them and what their needs were. That's not to say it was always a rosy situation but it certainly did help to put the people in neighborhoods and let people get to know them. Which is the only way, I think we could have done it. Otherwise if we had, we would have never been able to do it. If we had had to just force—we did force our way into the communities. There's no question about that. But if people were allowed to not allow them into the communities we would have never been able to get to what we have now which is a very, very good community system of residential services which are small, which are dispersed, and some folks don't even know there's one in their neighborhood. It's much different now than it was when we started out. We had three group homes in Summit County. We started with one group home and added two more and they were all large. Immediately we knew because of the opposition we had to try to get those into those neighborhoods that we really had to get smaller and more dispersed. So we went to that immediately. We created some community residential nonprofit organizations to run the ARC. I was the director of the ARC. We did not want to be in direct service. We wisely chose to remain an advocate and be able to monitor the services and so we supported the development of community residential facility programs, such as Ardmore, in this community and what is now called Evant? in this community. At that time it was called Metropolitan Akron Residential Services. With those there grew of number of even smaller agencies dispersed around the community to offer those services.

Jeff: Let's go back to the institutions for a minute. How did you as an advocate address the collective horror that you beheld and you saw in the institutions around the state? What was your strategy for change?

Ray: Our strategy and it wasn't just isolated to me but it was the advocates around the state, our strategy was with the ARC of Ohio, which used to be the Ohio Association for Retarded Citizens became the ARC of Ohio, the strategy was to close all the institutions. There was a position that was taken. I chaired the task force at the time that proposed the position to the ARC of Ohio that within five years this was back in 1975, that by 1980 we would have all institutions closed. Well, that didn't happen. But that's still the position of the ARC of Ohio that all institutions and we defined what an institution was at that time would be closed.

Jeff: The resistance that arose both on behalf of the unions that worked within the institutions and also some parents, can you talk about why parents and why unions do not want to see the institutions closed.

Ray: Well, for the people who worked in the institutions it was their livelihood. That's why they didn't want to see those institutions closed. That's what they knew as a job. That's what they did for a living. For parents it was that they didn't trust that there was any other alternative for their children. They didn't think their children would be accepted in the community and even those after it was demonstrated that those children and adults could be accepted in the community there was still resistance on the part of parents that wanted their individuals to be more isolated and to be what they felt removed from a community setting. We were able to demonstrate over the years, probably the first 10-15 years of deinstitutionalization as we called it then that we could take care of people better in the community than the institution could care for them. As that began to happen more and more parents began to feel that that was possible but there were always and still are parents who believe that the institution is the best place for their individual and especially after they began to be cleaned up. When we began the depopulation of the institutions and demanded that they be cleaned up and that the people be better served that had to live in them, then it became clear that we could depopulate and we could provide smaller settings although they were institutional they were better than the old large congregate living situations that we initially went into. They didn't start out to be the horror places that they ultimately became. They were seen as hospitals that were treating people medically for their condition of mental retardation. They didn't start out being filthy, dirty places. They started out to be operated largely by medical people who were trying to meet medical needs in the settings that they called hospitals at that time. These quickly turned to because of the numbers of people that began to be placed in them and because of the lack of dedicated people who would work in them became places where kids and adults were abused. Many, many children were placed there shortly after they were born in the institutions and grew up in institutions at that time. It was only in 1972 after I began working in this system that we saw people, and it wasn't because of me but because people generally feeling that an institution was no place for children. So you didn't go to an institution any more until you were of age whatever that became and that became the age of maturity at that point. But even then we were able to demonstrate that people could remain in the community and not have to be placed in an institution because of the care they got through their childhood in the community.

Jeff: I'm wondering about the principle that the children so many of the stories we've heard are from people who were institutionalized in their early teens or in my brother's case when he was eight. In the '70s it became the age of maturity, is that the way it is today?

Ray: Yes, there are institutions that serve children but they are community-based institutions largely. Heady Arlam? is an example of such an institution. It does serve children. They are smaller in nature. They are usually people who are severely disabled that live in those particular smaller settings. But people who lived in the large institutions back in the early 1970s; there were a lot of children. They had crib wards for children and they called them crib wards. The people you saw there were in cribs, were largely naked, or with a diaper on even to an older age to a preadolescent age or even an adolescent age at times. Some adults, it carried over when they became adults, they were still in diapers. They were never toilet trained, never able to meet their own needs as far as cleanliness and taking care of their bowels, taking care of their urinary needs. It just didn't happen for them. That was part of, I think the horror, when you walked into a ward not only the smell but the sights and the sounds of the people who were very unhappy to be there, very animal like in their actions because of neglect and starved for affection largely. So it was to walk into a ward in 1972 in an institution in Ohio such as Apple Creek was a horrifying experience for somebody who had never been there before, one of which was me.

Jeff: Are there people today who are still sent to institutions?

Ray: Yes, there are but it isn't a matter any more of being a remandation? to the institution. Now it's a voluntary admission and it's also a voluntary exit if they want to exit the institution. That was a second part of it. Once you were institutionalized before that when it was a legal admission that was made, it was probably very difficult for a person to ever leave until later on in the '70s when they did away with the legal—I'm trying to think of that term. I've been away from it long enough to forget some of these things and some of those terms. But we've gotten away from people that are placed in institutions under the law and sentenced there so to speak such as a person would be sentenced to a prison and gotten to a point where they're voluntary admissions now and people may voluntarily leave the institutions as well which is much different than it was when I began working.

Jeff: So for some families and some individuals today there's a voluntary selection of that environment, that life style.

Ray: That's true.

Jeff: In your opinion what would the profile be of someone for whom today's institutions would be the most appropriate setting?

Ray: For me there wouldn't be such a profile. Every person can be served in a community setting. There's nobody that I could ever meet that I believe would have to be institutionalized.

Jeff: Do you think the voluntary nature of that choice today is based on lack of information about other options?

Ray: In some cases I believe it is, yes. In some cases it's that they've largely been forgotten by the people who placed them there. Or people who placed them there are gone.

Jeff: I'm speaking of people today who make that choice.

Ray: Today, very few people make that choice today. I don't believe that very many people at all would make that choice today given the opportunity to compare the settings. There has been a dramatic cleanup of the institutions. They've been made smaller. They've been made more pleasant. They've been better operated. There's no question about that. And for some people they are in the community, for example Columbus Developmental Center is in Columbus, the city of Columbus; whereas Apple Creek Developmental Center is on the outskirts of rural Apple Creek, Ohio. So it's not in a setting that is in the middle of the community. But even the setting in the middle of the community that will serve 250 people to me that's too big and it doesn't need to be done that way. These people can be served in small scattered site settings and in their own neighborhoods where they are accessible to the people who love them.

Jeff: What have you seen concerning the pattern of family involvement with those people who moved back to the community?

Ray: Much, much more, much more involvement on the part of families. I believe that the families themselves after they've experienced the person being back in the community and seeing such an improvement in the person that they want to interact more with the person. They want to visit more. They want to have the person come visit them and that's often what happens is that there's more and more family interaction on the part of the person. It's very important to the person to have that kind of interaction with family members. Just like it is for all of us. So we see that has improved, we know that has improved the behavior of people as they live in the community and has prevented the deterioration of the behavior that we've seen in institutions especially large settings.

Jeff: Your perspective is a unique one as we've been gathering oral histories. Every person has a story to tell but yours has been particularly with the ?? Are there areas that you think are important we have missed?

Ray: I think you've covered them. I would want to add one thing that I am a parent of a 22-year old daughter who has Down syndrome developmental disability who many years ago would have had only the option of an institution or living at home with no services available to her. I've seen my daughter grow tremendously because she is able to live in this community. That she has gone to school with normal children not only in public school but in a parochial school. She has gone to a parochial high school that has a special program for children with developmental disabilities. She is exploring the workforce in this community right now as to what she can do to maintain a job in this community. For us she is a delight to have living with us and she wants to live with us at this point of time. That won't always be possible but in our case we have a family that's large, a very large family, where she will be family situated for life and we think that's important for her. I just wanted to throw that in and not only was I a professional and in some ways still am a professional in this field but that I am a parent of a child with a disability. ?

Person: Jeff, I'd like to ask a couple questions also. We talk a lot about what the institutions ? did to the people that were in institutions ???what did you see it do to families to moms and dads, did you see guilt or shame or relief or what was it that happened to moms and dads when this happened to their child?

Ray: Well, there were two types of moms and dads. One put their child in an institution and forgot about them. The other became very active with that child in the institution in fact became attached to the institution itself and that kind of a setting. That's where we got the people who are defensive of institutions today. It's not their fault. That was the option that was given to them but they maintain contact with their child. Many people did not maintain contact with their children and those children were neglected.

?Person: Was it because they were told that severing the ties??

Ray: Many times that is what they were told by medical professionals who told them put your child in that institution, forget about them. Forget they were born. I could never do that with a child of mine so it had to be terrible to hear a professional who you respected to say that and force yourself to believe that. But many people did and never had any interaction with their child any more.

?Person: The other question is one of the reasons why we're doing this is not only to allow people that have that important history to share but again lest we forget so we don't do it again. After all your years of service, your decades of service, do you see that we're safe now and everything is in place and we'll never have that same kind of concern again?

Ray: I do not see that. I see as long as a large congregate facility even 150 people or 100 people exist in this community, it's a threat that we could go back to that kind of a system. I won't feel safe until they're all gone; until every individual with developmental disability lives in their community of choice and is supported in their community of choice or who has a productive role to play in their community of choice. Everybody can't have a productive role.